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Comprehensive Lifestyle Support for Adults with Challenging Behavior: From Rhetoric to Reality

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Abstract: As a family we have made a sustained effort, expanded on a daily basis over the last 11 years, to support our son, JT, to “get a life.” Nothing that we have done in our professional work has been as challenging or as rewarding as discovering the authentic meaning of “comprehensive lifestyle support” that is present on a day-to-day basis. Our journey toward attaining this goal has been both harder and easier than we ever imagined. In this article, we describe JT’s life as it is today and review the lessons we have learned, hopeful that our successes and failures, and our process, will be useful to others.

Who Is JT?

JT is (if we may say so) a handsome 31-year old man. His love of life—his *joie de vivre*—derives from his relationships with his family and friends and from his soulful love of music. Those facts are often obscured under his four “labels.”

When JT was an infant, he received the label of low-moderate mental retardation. In his adolescence he acquired the label of autism. In addition, within the last two years he acquired the labels of bipolar disorder and obsessive-compulsive disorder. Much is written today about people with a dual diagnosis, and JT definitely has challenges related to cognition and mental health. When he is at the stable point of his bipolar cycle, JT is cheerful, relational with others, and self-determining. He derives genuine pleasure from his many activities. When he slips from that stable state into depression, he becomes sad, socially aloof, and nearly incapable of making a decision. And when he accelerates into the opposite polarity, he can be excessively cheerful, often silly and baby-like; he engages in extensive self-talk rather than interacting

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with others, has difficulty sleeping, and is unyieldingly insistent on having his own way. One of our greatest challenges is to choreograph and calibrate his supports in light of his rapidly changing moods and anxiety levels which vary not just week-to-week, but sometimes as often as hour-to-hour.

Although JT is 31 years old, we continue to be challenged by mood and anxiety states that we do not fully understand. Mental retardation seems “simple”; we shudder when bipolarity captures JT or when OCD imprisons him. Table 1 describes three points on his mood cycle and Table 2 describes three points on his anxiety cycle. When he experiences excessive anxiety, he tends to display the obsessive compulsive behaviors that are listed in Table 3. The bottom line is that JT presents enormous complexity.

We currently are collecting data on JT’s mood and anxiety states as well as his OCD behaviors and the nature of short and long-term schedule changes. Although at this time we still don’t have a sufficient understanding of all of these dimensions, it appears to us that JT’s most challenging behavior comes when his mood cycle is in a depressed state and his anxiety cycle is at a high level. The combination of low mood and high anxiety appears to lead to the OCD behaviors with the worst one being absolute “fixation” on hair. During these occasions, JT frequently engages in repetitive verbalizations about hair, attempts to touch hair, and even pulls hair very aggressively. Although

TABLE 1**JT's Mood Cycle**

<i>Depressed</i>	<i>Happy</i>	<i>"Wired"</i>
Stays in bed most of day	Good sleep; smooth a.m. wake-up	Difficulty sleeping
Extreme fatigue	Moderate energy	Jittery, rapid movements
Socially aloof	Relational with others	Excessive self-talk
Tight, tense face	Relaxed face	Rapid eye blinking
No pleasure from preferred activities	Genuine pleasure from activities	Silly laughter, excessive affect
Poor appetite	Appropriate appetite	Excessive appetite
Inability to be cheered up	Cheerful	Excessively cheerful
Inability to make up mind	Appropriate self-determination	Excessively insistent on own way
	Not flushed, not sweating	Highly flushed, noticeable sweating

this was behavior in which he engaged about eight years ago, it has only recently returned and has been highly problematic for the last several months. We often say that JT is our best professor, but the major problem is that he continues to give us the final exam before we've had the course!

What is Comprehensive Lifestyle Support?

Comprehensive lifestyle support often is the purported goal of positive behavior support. As stated by Carr et al. (1999): "The goal of positive behavior support (PBS) is to apply behavioral principles in the community in order to reduce problem behaviors and build appropri-

ate behaviors that result in durable behavior change and a rich lifestyle."

There is, however, no consensus about the meaning of a rich lifestyle. There is, however, a consensus on the technique to achieve it, namely through comprehensive intervention.

An intervention is comprehensive when it (a) addresses all problem behaviors performed by an individual; (b) is driven by the functional assessment; (c) is applied throughout the day; (d) blends multiple intervention procedures (change in structure, instruction, consequences); and (e) incorporates procedures that are consistent with the values, skills, and resources of the implementers. (Horner & Carr, 1997, p. 94.)

TABLE 2**JT's Anxiety Cycle**

<i>Excessive Calmness</i>	<i>Appropriately Calm, Relaxed</i>	<i>Excessive Anxiety</i>
Tuned out of communication	Appropriate, reciprocal communication	Highly repetitive
Tuned out of typical schedule	Appropriate interest in typical schedule	Highly fixated on typical schedule
Tuned out of anticipated events	Appropriate interest in anticipated events	Highly fixated on anticipated events
Doesn't initiate conversation	Talks about appropriate topics	Talks about hair
Shows excessive aloofness to females & "feminine objects"	Appropriate interest in females & "feminine objects" (hair, bathrobe)	Touche/talks about females & "feminine objects"
Doesn't express preferences	Expresses preferences/able to delay gratification	Refuses to delay gratification
Aloof	Appropriately engaged and demonstrates typical skills	Highly disoriented, confused

TABLE 3**JT's Obsessive-Compulsive Behaviors**

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- Flushes items in toilet
 - Talks about hair
 - Touches hair
 - Pulls hair
 - Talks about baby powder
 - Pours out liquids
 - Tears items
 - Talks about glasses
 - Breaks glasses
 - Goes to bathroom
 - Shuts doors
 - Gives inappropriate compliments to females
 - Talks excessively about females
-

Implicit in the Carr et al. (1999) and Horner and Carr (1997) approaches is the premise that an intervention, or several of them, can indeed address “all behaviors.” In JT’s case, interventions would address those impairments associated with the rather stable condition of mental retardation and the variable conditions associated with autism, bipolarity, and OCD. Also implicit is the premise that the interventions are applied throughout the day. In JT’s case, they are integral parts of his daily routines and of those who interact with him, such as his family, housemates, coworkers, and friends. Those two premises should be put under the microscope, for they are formidable to achieve.

Prelude to Getting a Life

When we first started working on comprehensive interventions, we had no idea how encompassing our task would be. Creating comprehensive supports 24 hours a day, seven days a week, 52 weeks a year, is a daunting task in and of itself. We have learned over the years, however, that JT does not just need one all-purpose comprehensive lifestyle support plan. Rather, he needs plans to be calibrated according to his mood and anxiety cycles and the interaction of those two cycles. Allow us to recount how we learned that lesson.

When JT was 19 (1987), he was terminated from the only adult agency in our community because of a mismatch between the program’s services and his challenging behavior. His

program involved being at the high school half a day and being at the local adult agency the other half-day. He did not believe that he “had a life” in either setting. Within the adult agency, his behavioral challenges escalated to daily occurrences. He frequently was aggressive toward others, refused to get up in the morning, and destroyed his personal belongings. It was a nightmarish experience for him and for us as a family. We were getting daily telephone calls reporting in excruciating detail his most recent behavior. We dreaded hearing the telephone ring, for it always seemed to herald another round of devastating news.

A moment of reckoning came for us when a good family friend commented to us: “No matter how far down the wrong road you go, if it’s the wrong road, turn around.” We realized that the road of traditional services would never lead us to the destination of our visions. No matter how hard the agency staff and we worked or wanted things to work out for JT, he and we were simply on the wrong road.

Indelibly imprinted in our memories is our last meeting with the agency director. That meeting resulted in JT’s withdrawal from the agency program. We quit and he was expelled, simultaneously. That parting being a given, we described for the agency director our vision of JT having a home, a job, friends, and places where he could hang out in the community. After listening to our visions, the administrator asked, “What are you going to do when you fail?” This was his not-too-subtle way of reminding us that his agency was the only program in town and that we probably would have to return to it, put our names on the bottom of the waiting list, and wait for traditional services. At that point, Rud responded, “We’re not going to fail; we’re going to succeed. And that’s not a threat, it’s a promise.” Making the promise, however, proved much easier than keeping it. How we tried--how we keep on trying--is worthy of extended discussion, for therein lie the lessons for others.

General Components of JT’s Life

It is impossible to capture on paper the many components and compositional nuances of JT’s lifestyle. Table 4 provides a snapshot of his daily and weekly schedule. The six key components

TABLE 4**JT's Weekly Schedule**

<i>Time</i>	<i>Monday</i>	<i>Tuesday</i>	<i>Wednesday</i>	<i>Thursday</i>	<i>Friday</i>	<i>Saturday</i>	<i>Sunday</i>
7:00-8:30 a.m.	Morning routine with Stacie	Morning routine with Anne	Morning routine with Stacie	Morning routine with Anne	Morning routine with Stacie	Morning routine with Rud	Morning routine with Rud
8:30-9:00 a.m.	Breakfast at restaurant with Stacie	Breakfast at home	Breakfast at home	Breakfast at home	Breakfast at home	Bakery with Rud	Breakfast at home
9:00-9:45 a.m.	Bus	Bus	Bus	Bus	Bus	Workout with Katie S.	
10:00-12:00 p.m.	Work	Work	Work	Work	Work	Errands with parents	Church with parents and grandfather
12:00-12:30 p.m.	Speech and lunch with Loren 12-1 p.m.	Lunch with Katie T.	Lunch with Katie S.	Lunch with Marilyn	Lunch with co-workers	Lunch with parents	Lunch with parents and grandfather
12:30-2:00 p.m.	Work	Work	Work	Work	Work	Visit grandfather	Hang out with parents
2:00-3:00 p.m.	Take bus home	Take bus home	Take bus home	Take bus home	Take bus home	Visit grandfather	Hang out with parents
3:00-6:00 p.m.	3:30-4:20 Music class	Workout with Jennifer	3:30-4:20 Music class	Speech with Loren/ Workout with Jennifer\	3:30-4:20 Music class	Hang out with parents	Hang out and dinner with parents, sisters, and grandfather
6:00-9:00 p.m.	Dinner with housemates and guests	Dinner with housemates	Natural Ties	Dinner and music with Mike	Dinner and music with Terrie	Dinner with parents: watch Statler Brothers	Grocery shopping with Richard
9:00-9:30 p.m.	Evening walk	Evening walk	Evening walk	Evening walk	Dinner and music with Terrie	Hang out with parents	Evening walk

are friends, home, work, “Cheers connections”, transportation, and family.

Friends

JT's life. As we recall JT's life before leaving the adult agency, we remember how very few peer friendships he had. True, he had many family friends and numerous social outings with people who were paid or who were receiving practicum credit for being with him, but he rarely had peer friendships during his childhood and youth.

Because friendship necessarily involves a give-and-receive exchange, we determined to create friendships; we were dissatisfied with JT being a “client” or “practicum recipient.” That was fulfilling to neither JT, us, nor, in most cases, the dedicated and lively young people who were his “providers.” There is nothing inherently wrong with a “client/practicum relationship” but there is vaster richness and fulfillment in a friendship.

Over the last 10 years, we have placed a high priority on creating opportunities for JT to have friends and to be a friend. Because friends are people who have a common ground, a number of his friends are musicians who share his passion for music. One of our most valuable friendship facilitators is Dr. Alice Ann Darrow, a member of the music therapy faculty at The University of Kansas.

For 10 years, Alice Ann has been the link between her students and JT, selecting her students to do their practicum experiences with him and, over time, to become his friend. Over the years, JT has hung out with these friends, gone to community musical events with them, received formal music, therapy, had dinner with them on a regular basis, and has even had some of these music therapy students/friends as his housemates.

The lesson that JT, Alice Ann, and her students have taught us is two-fold. First, find a door-opener, a person or entity that can pry open the doors that exist between those with disabilities and those without disabilities who share the same interests, so that friendships can evolve; friendship requires an open-door policy. Second, connect the door openers to JT's passions (in his case, music); friendship requires a common ground. Here's an example of how JT and Mike Brownell, a current music therapy student, have

combined music therapy and friendship facilitation.

There are two major foci to JT's involvement with music therapy: decreasing problem behaviors and increasing overall quality of life. Because of the ease with which JT memorizes song lyrics, it becomes natural to use this modality to impart important information by changing lyrics to familiar songs or creating new songs. The lyrics might include a simple task analysis of what JT is or is not supposed to be doing in a given situation. Some behaviors that we have addressed include pouring mouthwash down the sink (to the tune of “Let It Be”), getting up in the morning (to the tune of “Wake Up, Little Suzie”), and hair pulling using original lyrics that JT is currently helping create. To increase quality of life, my goal as a music therapist is to increase the breadth of JT's relationship with music. One of JT's greatest accomplishments since I have been working with him has been learning to play the guitar. With minimal cueing, JT is able to play simple folk songs on his guitar and sing simultaneously. This provides the opportunity for success in a medium in which he feels intense pride, and can be used as a basis for interaction with his other friends. As one of the most capable individuals in his group music therapy sessions, JT is able to put his musical facility to work as a model and leader to others in the group, a position he might not frequently be afforded.

As much as I have tried to teach and do for JT, he has returned as much in kind. JT's musical abilities are every musical therapist's dream. His enthusiasm and passion for the medium is both inspiring and instructive. He has demonstrated to me, more than any other client or friend, the capacity of music to change behaviors and to forge friendships. JT's affinity for music has enabled him to relate on some common ground with old and new friends, co-workers, and family members alike. (Mike Brownell, friend and music therapy graduate student.)

Friendship for JT is like friendships among people who do not have disabilities; it spans various types of people and is multi-dimensional.

Entry into friendship does not have to be based on a single set of door openers, a single set of people. For example, JT has lunch each Wednesday with a college student, Katie Schwarzburg, who was our next-door neighbor when she was in elementary through senior high school.

I've known JT since I was a little girl, so being a part of his life came very naturally to me. JT and I have had our good days and not-so-good days together but usually we have good times. I have lunch with JT on Wednesdays and workout and/or have a snack on Saturday mornings. I have found the time I spend with JT to be of great value. He has inspired me to become a special educator. He has taught me patience, because I have had to wait for him to answer me or to catch up to my speed of doing everything. Although I am there to be JT's friend and helper, I have found I am the one who has been helped. For example, some elementary-school students once teased JT when we were taking a walk near his home. I wanted to chastise them, but JT just ignored them. He taught me about hostile and forgiving attitudes and about the security of being comfortable with one's self. I have found JT to be totally honest and amazingly aware of his surroundings. The more time I spend with JT, the more I learn about him and I learn about myself. I truly value the time I get to spend with JT. (Katie Schwarzburg, friend and KU undergraduate.)

Friendships based on a 1:1 ratio—such as those we have just described—are perfectly fine, but they do not exclude “group friendships” such as many people without disabilities experience through membership in various groups. For JT, the group friendship that he most values occurs each Wednesday night (and at other occasions) when he participates in “Natural Ties.”

Natural Ties is a student-directed organization in which KU students and adults with disabilities get together on a regular basis to share friendship and enjoy themselves. Although most of the adults with disabilities in Natural Ties are matched with KU campus organizations, JT has a match with five students (the “Jackson Five,” so-named because they all love music), rather than an organization. Their Wednesday night activities include country line dancing (JT's favorite),

bowling, movies, dinners, and similar group activities. Sarah Ellestad is a KU student who is JT's friend in Natural Ties.

I guess to describe my relationship with JT would be the same as if someone had asked me to describe my relationship with any of my other friends. When I think of true friendship, I think that it means being able to love someone for all of their good qualities and then being able to love them even more for their not-so-good qualities. So, I will describe my relationship with JT based on this definition.

First of all, I know that JT is a good friend because when I am with him, I can sing old, goofy songs as loud as I want and dance around in my truck while driving down the street and JT will not make fun of me. In fact, he joins right in with me, and if I listen closely enough while he sings, I can catch all of the words to the songs that I could never for the life of me figure out. But, this is just one reason why JT is my friend. I could talk about JT's sense of humor or how he has the ability to cheer me up without even knowing it, just by giving me a “soft five” or saying, “You look nice today, Sarah.”

However, like myself and all of my other friends, JT also has his faults. For example, I guess I never will understand why some days JT will not get out of bed even if he knows that it is Wednesday, the day we go to Natural Ties together. Although I do not understand why he does this, I do know how much he loves Natural Ties. Furthermore, I know that if JT misses Natural Ties, he must really be going through some rough times. There were also a few days in the last months when I went to pick JT up that his roommates warned me that he recently pulled someone's hair. This information is always followed by strict orders to bring JT home if I see even the slightest sign of such behaviors. Again, I don't understand why he sometimes pulls people's hair because I know that he is not the kind of person who would purposely try to hurt someone. I have never seen this side of JT, but I know that it does exist. Of course, I hope that I never see the day that JT pulls my hair. However, I do know that if it does

happen, there is no way that I would ever stop being JT's friend.

When it comes down to it, my friendship with JT really does not differ from any of my other friendships. Like all my friends, JT has his share of faults. Of course his faults may differ from others, but then again, not one of my friends is like the other. Furthermore, I know that JT is my friend because of all of the things I like about JT allow me to truly accept him for who he is despite our differences. (Sarah Ellestad, friend and KU undergraduate.)

Challenging behavior can impair friendships. On a few occasions, JT has pulled his friends' hair, and on more occasions he has broken their glasses. His friends need information and support in how to handle these behaviors, especially when he becomes fixated on hair and ponytails. There are times when we worry at our innermost core about JT's hurting his friends when his mood, anxiety, and behaviors are at a very difficult place. We also worry about how open to be with his friends from the outset. When he is in phases of having very few challenging behaviors, we don't want to share information with friends that will make them afraid of him or put off by him. It's difficult to balance the equation: how much to tell people and how much to withhold.

Pointers for facilitating friendships. What lessons do we derive from JT's life-style pursuit, where friendships are the ingredients of that "rich" life-style?

- The development of friendship should not be left to chance. Everyone in JT's network needs (and all truly want) to be on the lookout for people who might be interested in being friends with JT and to think about how to introduce those people to JT. We have to be lucky in friendships, but we have to be deliberate, too.
- Before several of JT's long-time friends have moved out of his life, they have "recruited" people who might be interested in being his friend and brought them along on outings for a couple of months before their own departure. In this way, they leave no hole in JT's network but take personal responsibility to replenish his social network. Personal responsibility—derived from friends' sharing in his life—creates opportunities for others; there is something inter-generational about friendship, some quality of it that impels others (JT's friends) to want to share it with others.
- People who are new to JT's friendship network need information about his disabilities and variable behaviors and how to best connect with him during his difficult phases. They often have questions about behavioral manifestations that occur in JT's different mood and anxiety cycles (Tables 1 and 2) and also about how to deal with the obsessive-compulsive behaviors (Table 3). They need to feel comfortable having someone that they can talk with about how they can best support JT when he is engaging in unusual behavior. JT is not the only one who has anxieties. The goal is to quell his anxieties and those of others, too.
- It is helpful when newly introduced people are getting to know JT if they can hang out with him and one of his long-time friends during the "warm-up process." JT is both easy and hard to know—easy when he is in his "stable state" but hard at other times. The job is to create both knowledge and comfort levels among his friends.
- We have parties at least several times a year, each one attended by many of JT's friends. These "happenings" help them to get to know each other. The more we build a sense of community around JT, the more the communal sense gratifies everyone else.
- Each semester, a speech and language student works with JT in a practicum arrangement. Several of these students have worked with JT in learning important information about his friends (e.g., their birthdays, names of their pets, favorite television shows, and upcoming plans) so that JT can more easily engage in reciprocal conversations with them. This makes him a more interesting conversation partner and also "lightens the conversation load" because JT can help carry it. Words, not just music, connect people. Enriching JT's lifestyle means helping him find the words that have meaning to others.
- With the assistance of his housemate, Anne Guthrie, JT daily e-mails his friends. He dictates what he wants to say, and his words are typed into the computer. Nearly every-

one likes to receive a cheerful note; JT and Anne make that possible, and, by so doing, they invite others to reciprocate.

- We provide support to JT to remember his friends on special occasions through gifts or other types of thoughtfulness. Being a friend means acting like one, and giving on others' special occasions is an especially memorable way of demonstrating friendship.

A Home of His Own

JT's life. JT has lived in his own home for almost 10 years. We have been in the most fortunate position of being able to purchase a three-bedroom ranch-style house in a neighborhood that is near the university. It is a stable neighborhood, and his home is on a bus route to the university, where he works.

The title and mortgage are in our names, so we receive a tax deduction on our income tax for the interest on the mortgage and for the real estate property taxes we pay. But JT earns enough to pay the mortgage (principal, interest, taxes, and insurance) with his monthly salary, and he makes his net income available to us for that purpose.

JT has two housemates who live with him without paying rent or utilities. They do not receive any wages, but their basic housing expenses are covered. Each provides JT with approximately 12-15 hours of personal support a week. We do not have any formal "job description" or "duty list." Each set of roommates individually negotiate with each other, JT, and us to develop a routine with which everyone feels comfortable.

Over the 10 years, JT has had 15 housemates—always two at a time. Their shortest stay was a couple of months; the longest, 2½ years. On two different occasions, the housemates have been a married couple (as they are now), and at other times, there have been two single people. We have found housemates through friends in the community who provide services to individuals with developmental disabilities, through JT's friendship network, and through general word-of-mouth.

JT's week, as reflected in Table 4, includes being at his home throughout the workweek and then coming to our family home on the weekend. The weekend change allows JT to

connect closely with us and provides his housemates an opportunity to pursue their own interests. If and when JT qualifies for the Medicaid Waiver in the future and we have additional financial resources to pay for support through a self-determination program option, he may well stay at his own home on most weekends with weekend companionship paid for through his financial resources.

All of JT's housemates have had unique strengths, preferences, and needs. JT's current housemates, Anne Guthrie and Richard Gaeta, excel in creating a home with warmth, caring, hospitality, and delicious food. Richard is an outstanding cook, and JT and his friends are extremely fortunate to reap the benefits of Richard's culinary talents. In addition to preparing wonderful food for the three of them, Richard, Anne, and JT also routinely invite guests over on Monday evening. They have an enjoyable evening of friendship, conversation, laughter, and delicious food. This is a way for JT to be reciprocal with his friends, providing unique opportunities for their enjoyment.

We have tried to avoid having JT's housemates become "residential staff." But we also have tried to make it possible for them to support JT in a professionally competent way, for he needs various kinds of support in daily-living skills and he especially needs emotional/behavioral support at those times when his bipolarity or OCD behaviors become problematic.

The role of housemates of people with challenging behavior has received scant attention, although it is critically important. The fundamental issue is how to develop a relationship so that the housemates and JT are truly tuned into each other and have a relationship that fosters JT's self-determination and sense of security. Housemates also have to be prepared to assist JT with some personal needs, go through the phases of challenging behavior, problem-solve with his family and friends, and help schedule and coordinate his multiple activities. One of JT's current housemates, Anne Guthrie, describes the relationship that she and Richard have with JT.

After nearly 1½ years of sharing JT's home, Richard and I think the three of us *almost* have the rhythms of our co-existence down. We hope JT shares our opinion. What has

been essential for all of us is the continuous availability and support of JT's family and longtime friends. This was especially critical during our first few months as housemates when we were still learning to interpret JT's verbal and non-verbal communications. The process of negotiating shared space and routines, providing pertinent information, and honoring preferences is most easily accomplished through clear communications. And, although JT is more than capable of recalling complex song lyrics, and the names of long lost friends, as well as their favorite expressions (Heavens to Murgatroid!), his ability to express his feelings, describe a situation, or explain an action are limited and unreliable. Thus it was important to have his circle of family and friends available to JT to help him explain his preferences for such things as furniture arrangement, assistance in personal care, and relaxation activities. JT's adjustment to having two new people "intrude upon his home and routines" would surely have been more tumultuous without this support.

Though we all seem to be more adept now at understanding each other's spoken and unspoken languages now, JT's inability to verbally communicate his needs during episodes of especially challenging behavior—times when he is typically less responsive—still causes great frustration for us and all who know him. At such times, the support of a second housemate and/or others close to JT is vital. Housemates' negotiations with each other are essential. We have done this through establishing a routing whereby Richard typically is available to JT for certain parts of the day, while JT and I typically spend other times of the day together. While we frequently do things altogether, or individually, it is helpful to have a routine to fall back on at difficult times, both for JT's reassurance and for our own need for respite.

The most chronic and problematic of JT's challenging behaviors at home is his extreme difficulty in getting up in the morning. When he is depressed or anxious, he often simply will not budge from bed. So he now has a "morning

coach" who comes three days a week, and Anne is his coach on the other two days. They use a very specific behavioral program of prompting, usually but not always with success. For as long as we can remember, he has missed work more frequently than we would prefer—usually at least one day a week. On days that he does not get up, he loses all of his special daily activities. This has created a "hardship" on his housemates because he typically stays in bed for the major portion of the day and then is at loose ends in the afternoon and evening, having no organized activities.

As well will describe later, we are also his employers—he works at the Beach Center which is the program we co-direct at The University of Kansas. As his parents and employers, we concluded that his attendance record was unacceptable. Recently we have started a new program where he can either get up on his own with the assistance of a morning coach or one of us will come over to his house and serve ourselves as his morning coach. Interestingly, we have just been trying this approach for the last five weeks, and he has had absolutely perfect attendance! We have only had to go over to his house one morning, but we have talked with him on the phone on a number of other mornings. We believe that he is learning that coming to work is non-negotiable unless he is sick. Because he very much wants to be independent and "to be a man" as he describes, his preference is to clearly avoid our being his morning coach—and we definitely share that view since we have no desire whatsoever to be the morning coach!

Given JT's wide-ranging needs and his and our vision of a rich life-style characterized by independence from his parents and achievement of his own home, we have learned at least the following lessons.

Pointers for supporting JT to live in and enjoy a home of his own.

- All housemates have their own strengths, preferences, and needs. The focus has to be on building a home that is responsive to them as well as JT.
- We try to be as flexible as possible in backing up the housemates when they need to be away because of an emergency or they want to take time off. Likewise, they support us when we are not able to be home on the weekends.

Flexibility and informality are the ingredients of mutually responsive collective living.

- We need to explore creative ways of providing compensation to housemates if we want to be able to retain them for a long period of time. Having Medicaid funding (home and community-based services) may provide some of that funding.
- Researchers should interview housemates of people with challenging behavior to codify what they have learned about their important role. Veteran housemates might be available to support new housemates in “learning the ropes” of sharing a home with an individual with challenging behavior.
- Federal and state policies need to subsidize community-based living and home ownership for people such as JT. We are among the few families fortunate enough to have been able to purchase and maintain a home for him, independent of our own home. Most families cannot do that; they need policy assistance, whether in the form of tax credits, heightened tax deductions, or family support subsidies.

Work

JT's life. We must be candid at the outset: We ourselves make it possible for JT to have a job. That is so because we co-direct the Beach Center on Families and Disability at The University of Kansas; JT is a Beach Center employee, supervised and evaluated not by ourselves but by an independent person (so as to comply with university anti-nepotism rules). The fact of the matter is, however, that JT works with our support; that is not objectionable to the university, for, without JT as our “best professor” and inspiration, we would not have had the wisdom and the courage to create the Beach Center and the determination to have it be a force for change on behalf of families whose children have disabilities.

JT works from 10:00 a.m. until 2:00 p.m. five days a week as a clerical aide, doing such tasks as copying, collating, stapling, folding, stuffing envelopes, stamping, and delivering the mail and the huge amount of materials that we disseminate each week. His tasks are essential and would be completed by other office staff if he were not employed there.

JT has a job coach whose role is to provide him with instruction on new tasks, support him through his mood and anxiety cycles, and enable other staff to know how to best provide support to him. Jaimie Swanger, his current job coach, describes JT's work situation as follows:

JT's work at the Beach Center is essential to everyone who works here. JT's main role at the Beach Center is to collect and distribute the large amount of mail that comes in and out everyday. There are over 25 people employed at the Beach Center, and JT is responsible for all of their mail including federal mail, international mail and the campus mail that is collected from three different places on the KU campus. JT's mail routes keep him quite busy for the most part of his employment here. When JT has completed his morning and afternoon mail routes there is time allotted for JT to assist the office staff, by doing clerical activities like copying, stapling, collating, and putting together dissemination materials distributed by the Beach Center on a daily basis.

My main role as JT's job coach is to motivate JT to come to work on a daily basis and keep him busy learning new tasks and interacting with his co-workers. The Beach Center staff has been very supportive of JT through the years and consistently continues to support him through his different moods and anxiety cycles. Many staff members regularly ask JT for assistance on specific tasks, some mail related and others not. The staff interacts with him daily and count on JT being there for assistance, support or a friendly “soft five.”

Although JT is employed at the same organization as his parents, he counts on the central office supervisor and his immediate chain of command to delegate office work and monitor his appropriate work-related behavior. In the past when issues of inappropriate work behaviors occur, it is up to the central office supervisor to decide if JT can work the rest of the day, or if he needs a half-day off and go home. On the particular occasions of experiencing a difficult mood and/or anxiety cycle, the Beach Center staff pulls together to increase JT's work support by talking with him more, giving him more positive feedback,

or even taking him out to breakfast or lunch. JT's employment at the Beach Center is an ongoing learning experience for all of us who work with him. He enriches our lives in ways that only he is capable of. He works hard, giggles at our jokes and is continually available for assistance or a soft handshake. (Jaimie Swanger, job coach)

Would JT have a job like this if we were not his parents and in a position to hire him? Almost certainly not. We are acutely aware of how unusual it is for us to be able to make this opportunity available to our son. Providing this opportunity, though, also has its downsides for us. JT's performance and his behavior are always on our minds, given that we share the same work setting five days a week. When JT encounters problems at work or displays challenging behaviors, we have the ultimate responsibility for problem resolution. It would be refreshing to have respite from these employer-and-parent responsibilities, but overall, we accept the downsides in order to have this opportunity for JT.

Our vision is that JT will expand his hours either here at the Beach Center or in other employment. Jaimie has the most creative idea for his other employment:

It has always been my vision that people with disabilities are capable of working in the community in employment settings that highlight their particular interests, strengths, and abilities. JT has many strengths that have been utilized through his work at the Beach Center, but his passion truly lies within the world of music. It is my hope that at some point in JT's adult life he will be able to make the transition into the world of music-related employment. Everyone who knows JT understands that he loves music and uses music as a catalyst to improve his quality of life.

My hope for JT to enter into the world of music related employment would be that he would be able to host music related activities within the community. A production company could be run in JT's name that could portray to the community that his events are multi-cultural, wheelchair accessible and open to anyone who would wish to attend. JT could spend his mornings and afternoons public-

cizing his events to the community, which would involve research of organizations that might want to participate, producing flyers, and sending out information to individual community members.

JT's plan would be to collaborate with small business owners who would be willing to rent out their dance hall for maybe two nights a month to JT. He could charge a small amount at the door, work with local disc jockeys to choose music, and act as a host at the events. This plan would incorporate the clerical skills he has gained from working at the Beach Center as well as developing new skills in a field where his interests and abilities can truly be recognized. JT would need ample support in creating such an opportunity. He would continue to need a job coach or job developer and benefit from the use of volunteers on event nights. I hope that whatever JT wishes to do with his adult career, he continues to utilize the strengths and abilities he has as well as developing more skills that will keep him learning and motivated. (Jaimie Swanger, job coach)

Some of the types of problems that arise in the work setting include JT's staying in the bathroom for inordinate amounts of time, his lack of consistent work productivity (some days he is slow, but others he is highly productive), his highly repetitive language, his periodic fixation about the hair of female co-workers, his lingering during his mail route, and his shutting doors that people want left open.

The fact of the matter is that JT's employment at the Beach Center benefits not only him and ourselves, but others as well. His co-workers have described him as the "healer" when they are "down," as the "inspiration" when they are challenged by tasks at work or conditions in their own lives, and as the "morale maker" when he is invigorated and joyful.

They also recognize and accept, however, that JT is not always the leaven in their work. Like us, they have been required to come face-to-face with behaviors, moods, unpredictability, and instability as his bipolarity, OCD, mental retardation, and autism gang up on him from time to time.

JT has been aggressive only a few times when he has been at work at the Beach Center itself. That is problematic for staff; they, however, know

and are alerted by us and JT's job coach when JT may be on the cusp of being aggressive. With an alert comes accommodations from staff to JT—always simple accommodations that do not inconvenience staff or disrupt their and JT's work. But there are others in JT's workplace who are not so easily alerted or are not able (as our staff are) to detect the early warning signs that JT is apt to be aggressive.

The problem is how to normalize the workplace, accommodate JT's varying behaviors and states, and still safeguard others. An all-points bulletin about JT would have to be circulated among nearly a dozen different programs. This is so because his work duties require him to deliver and pick up Beach Center mail in three locations in two different building. In doing that particular part of his job, he passes by and thus poses safeguard issues with respect to Kansas University students in their classrooms and hallways, young children in child-study classrooms, employees in offices other than the Beach Center, people along the convoluted route he follows as he comes to and leaves the Beach Center from the bus stop, and the drivers of the buses he takes to and from work each day.

Pointers for increasing work success. It seems paradoxical—an unexpected outcome—that, from the hard times JT faces at work, there comes a solidarity of the Beach Center staff, a cohesiveness that only JT creates, a recommitment to him personally and thus to the collective mission of the Beach Center. When all of us here do something to benefit JT at the times he is most challenged and challenging, and when that “something” benefits us individually and collectively by teaching us more about challenging behaviors and causing us to rise to meet and overcome the obstacles of those behaviors, then we all benefit, and so do our friends and colleagues throughout the special education field. We learn what we have not learned before, or we relearn what we have forgotten, or we learn what no research yet seems to be able to teach. More than that, we acquire a sense of shared adventure as all of us—JT, parents, and co-employees—embark on a journey of mutual life enrichment.

- Because JT's work productivity depends in part on his mood and anxiety cycles, job coaching and work accommodations need to

respond accordingly. A static and uniform approach simply will not work.

- We find qualified job coaches who can work from 10:00 a.m. until 2:00 p.m. each day. The problem is that most people interested in such a job do not have sufficient training in positive behavior support to enable them to deal with JT's challenging behavior.
- To the extent that is possible, we make sure that our work setting does not escalate JT's behaviors or create inordinate tension for his coworkers when JT is at difficult points of his mood and anxiety cycles. We learn to be caring and sensitive to his needs without our own moods and anxiety levels cycling with his.
- We continually teach JT new skills so that monotony does not become part of his work.
- There is a fine line between supporting JT during the phases when he is showing signs that he may be close to aggressive outbursts and yet ensuring the safety and security of his coworkers. By being candid with everyone in his workplace about his anxiety and alerting them when JT is in a “hard” cycle, we balance these competing interests. Privacy is foregone, work is retained, and community is built.

“Cheers Connections”

JT's life. We use the term, “Cheers connections,” as a reminder of the chemistry that happened on the television program, *Cheers*, when people had a place to go where everyone knew their name. It is especially important to JT to have places in the community where he is considered a “regular.” Table 4 shows that he has many different “Cheers connections,” including his church, a fitness club, several restaurants, a bakery, and a grocery store. JT is a “regular” because he knows the routine in terms of what to do, how to behave, where the restroom is, etc. He also is a regular because many of the people in these places know him and his idiosyncrasies. They greet him by using his “soft five” handshake (his variation of “high five”) and the fraternity grip that he learned while associated with Sigma Alpha Epsilon chapter at Kansas University, and which he gives to nearly everyone (often to their dismay at first and then to their pleasure later).

JT's friends and family are especially important in helping him to maintain and even

expand the number of his “Cheers connections.” He looks forward to going to these places in the afternoons and evenings. Many times the anticipation of these visits provides him with the incentive he needs to get up in the morning. Indeed, his wake-up program in the morning is conditional: If he doesn’t get up and to work, he cannot participate in his “Cheers connections” activities in the afternoons and evenings.

The incredible value of having “Cheers connections” was illustrated for us just a couple of weeks ago in an incident which Anne, JT’s housemate, reported to us. She and JT were at one of the local breweries having dinner. JT needed to go to the restroom and ended up staying in the restroom an inordinate length of time. Anne became worried about him and was almost at the point of asking one of the waiters to go check on him when JT came out of the restroom. Later on during dinner, a waiter came by the table and asked JT if he was doing okay. He then explained to Anne that he had gone in the restroom just at the point where a man was about to grab JT and push him into the wall. As the story unfolded, the waiter found out that the man felt that JT was staring at him inappropriately, and he perceived that JT was propositioning him for a gay encounter. When the waiter walked in, he saw this incident and quickly defended JT and explained to the man that JT was not making an inappropriate advance to him. That’s the essence of a “Cheers connection”—when the “regulars” look out for you and vouch for you when problems arise that cannot be fully anticipated.

Pointers for facilitating “Cheers connections”

- It is critically important to make friends with the staff and regular patrons at the various “Cheers connections” and to provide them the information and support that they need in order to be comfortable with JT.
- Because there are often new people in these settings, JT’s housemate, Anne, made a wallet-size foldout card that he can give to people in some of these settings (see Table 5). The information provides a foundation on which people can begin to get to know him personally and to figure out how they can best provide support and friendship to him.

- We invite people from the various “Cheers connections” to JT’s parties as a way to bring them into his community of support.
- We tell the staff and regular patrons in the various “Cheers connections” just how much they contribute to JT’s quality of life and how grateful he and we are.
- When JT seems to be edging closer to challenging behavior, we encourage him to not go to the various “Cheers connections”, and sometimes we simply prevent him from going there, in an effort to try to prevent an untenable situation.

Transportation

JT’s life. In the earlier years, just after JT moved into his home, it did not occur to us that he would be able to use public transportation. After all, JT cannot make judgments about safety in crossing streets. His housemates and job coach, however, taught him to ride the city bus. He boards it at the end of his block, rides it to campus, exits, walks a complicated route across campus, and arrives at his work—all totally on his own. Fortunately, he can follow this route without having to cross a street.

We have become friends with the bus drivers, other passengers, and bus dispatchers through the years, especially as JT has experienced some ups and downs of behavior related to the bus. When he is in a particularly challenging phase, we worry about his being on the bus in terms of being aggressive to other passengers. That has never happened, and we “knock on wood” as we write this sentence.

JT has not always followed his work-bus-home routine. One time after he had failed to come home on time, we launched a search for him, looking in all of the buildings he passed through on his way to the bus stop from the Beach Center. We began that search because the dispatchers and drivers had told us that he was not on, and had not boarded, any bus that day. Fortunately, one of his coworkers finally found him in a hallway in a building on his way to work.

TABLE 5

JT's Fold-Out Card

Hi, I'm glad to have you as a new friend and I look forward to having some great times with you!
Because sometimes I have difficulty letting new friends know some things that are important to me, my friends and I wrote this for you to read and keep.

\$\$\$\$\$\$\$ MONEY \$\$\$\$\$\$\$

I usually have cash in my wallet, but need some help counting it. I also have a checkbook I like to use when I'm shopping or paying for a meal. You can help by filling out the check, then I will sign it and give it to the cashier.

!!!!!!! MY FAVORITE THINGS TO DO !!!!!!!

Music is my main love: listening, singing, dancing, also exercising, walking, playing catch, going to stores or movies, and eating out.

###! THINGS I REALLY DON'T LIKE ###!

Bad weather, slippery sidewalks, big hugs and hard handshakes, being talked to lots when I am trying to make a decision or I'm upset.

~~~~~ I SHOW THAT I'M UPSET BY ~~~~~

Saying "No" or "I don't want to" or else making a face or laughing a lot or clapping my hands fast or maybe saying my forehead is hot or my throat is sore.

~~~ THINGS THAT HELP ME CALM DOWN ~~~

Remind me to take some deep breaths, listening to quiet music, singing a slow song, *sometimes* getting a hug (ask me).

++++ THINGS I TRY TO AVOID DOING ++++ (PLEASE REMIND ME IF I FORGET)

Drinking lots of caffeinated drinks, touching and pulling people's hair, touching and breaking people's eyeglasses, touching people's car stereos without asking, shutting and locking people's car or room doors, talking about baby's things (like baby powder), taking down posters or ripping up papers.

Like you, most of the time I'm in a great mood—especially when I'm with my friends!

If you ever have any questions please call!!!!

IMPORTANT PHONE NUMBERS

My phone # is: 841-8275
(Anne and Richard are my housemates)

My parents' phone # is 843-9500
(Ann and Rud Turnbull)

My work phone # is 864-7600
(Jaimie is my job coach, my parents work there too)

On this particular day, there was a door that was ajar that usually was closed. Manifesting one of his OCD behaviors, he was trying to close the door, but it kept popping open. He had been repeatedly closing the door for several hours when his coworker found him.

There have been other times when JT has taken the wrong bus or has failed to get off the bus at the right bus stop. On all of these occasions, when his housemates realized that he was home significantly late, they called us; and we, in turn, called the bus dispatcher and sometimes the campus police. We are happy to

report that in all cases JT has finally arrived home safely.

Pointers for increasing JT's transportation success. There is something extraordinarily normalizing about JT taking the bus; many people do just that, and it is, in our town, a regular means of transportation. In addition, there is also something intrinsically developmental about JT being a rider: He knows he is accomplishing an extraordinary feat (extraordinary for people such as JT); and he feels more mature, more like a "man" (as he would put it). Indeed, when he rides, he becomes visibly proud; his chest and head are more erect, and he resists any offers of rides given by his coworkers on those days when he is especially

fraught with anxiety and apt to display challenging behaviors. The downside, of course, is that JT's behavior can be explosive; being a rider subjects him to the risk of public response (counter-aggression or police intervention). That is why we cannot take bus-ridership for granted but must devise strategies to make it possible and safe.

- It is critically important to form personal relationships with the drivers, dispatchers, passengers, and campus police officers, all of who provide a safety net for JT's independence in riding the bus.
- (Ironically, just as we were writing this sentence, a student came to our offices and told us that JT was downstairs outside of a preschool classroom with two campus police. After rushing to him, we learned that, rather than walking past the classroom on his way to the bus, he entered the classroom, touched a little girl's hair, and took her barrette out. Fortunately—very fortunately—he did not pull her hair. The teachers were alarmed and called the campus police. We then talked with the police, with JT, with the teacher and director of the preschool, and with one of the parents in the classroom who had learned about the situation. We spent a good portion of the next couple of days trying to get accurate information on exactly what happened and what we might do in the future to prevent a repeat of this situation.
- These are the sorts of situations that scare us to death in terms of what might have happened and how we can help ensure that JT is not aggressive toward the preschool children in the future. We ended up sending a letter to the preschool teachers that they could share with their staff, students, and others who come and go on this same hallway. This is a classroom that JT must pass every day when he walks from the bus to work and when he leaves work to return to the bus.
- When people live in the inclusive world, the positive behavior support must be highly dispersed. Interestingly, one of the campus police officers, Sylvester Birdsong, introduced himself to us as being a security guard at the time JT was in high school. He could not have been friendlier or more supportive. This is a good example of the importance of

personal connections. How ironic that this would happen while we were writing about forming personal relationships related to transportation!)

- One of the downsides of working at a university and relying on the university public transportation system is the academic calendar. Given JT's extremely high need for routine, it is especially disconcerting for him when the bus does not run during holidays and between semesters. Not having the bus run can be the type of schedule change that can escalate JT's anxieties.
- JT needs to have back-up transportation systems during the times when his challenging behaviors are most likely to occur. This could involve having a coworker or family member drive him or using a taxi with a driver who is especially connected with him.

Family

JT's life. Family is definitely the bedrock of JT's support system. When JT and we left the service system 11 years ago, we started down this new road of supporting JT to "get a life" through person-centered planning. Our version of person-centered planning is called Group Action Planning (GAP). GAP involves a *reiterative and long-term process* of envisioning great expectations and working together through group support to transform these expectations into daily and weekly supports (Turnbull & Turnbull, 1996; Turnbull et al., 1996; Turnbull, Turnbull, & Blue-Banning, 1994).

For several years, JT's Action Group met on a regular basis. Now we have evolved into a highly informal and flexible group. We gather the critical people across all of JT's environments on a periodic basis when new or recurring issues need to be addressed. On a regular basis, we meet with his housemates, job coach, morning coach, and a behavioral specialist to steer the overall efforts and trouble-shoot the problems that arise.

As his parents, we serve as JT's service coordinators. We help to orchestrate all of the previously described components. We are also JT's support on weekends and holidays. The advantage of this approach is that we have maximum flexibility to design his positive

behavior support and to advance his and our great expectations.

The downside of our approach is that it is an extremely time-consuming process. We truly regret that most of his service coordination and support falls upon us. Given that we both have jobs that take about 150% effort from each of us, in addition to having two children besides JT and an elderly parent for whom we provide daily caregiving, there is rarely an unclaimed minute in our lives. It is often hard to keep our energy levels sufficiently high to give JT's comprehensive life-style support network the time and attention that it requires.

Aside from the sheer number of hours that it takes to plan, implement, and monitor comprehensive lifestyle support, the emotional toll of challenging behavior on families (Turnbull & Ruef, 1996; Turnbull & Ruef, 1997) is often overlooked in the professional literature. As an example, a situation like JT's going in the preschool classroom and touching the child's hair is extremely worrisome. We feel today as we write this (just hours after the incident) that for many days and months in the future, we will continue to feel extreme anxiety about what might have happened and what could potentially happen in the future. A critical issue for families is learning to emotionally cope with the ambiguity of not knowing when or how the challenging behavior is going to occur and what potentially truly serious circumstances possibly await the horizon.

One of the keys is learning to handle both the pessimistic and optimistic possibilities that could accrue so that one can still have great expectations but without undue risks. People often say, sometimes rather tritely, that there is "dignity in risk"; but too much risk that results in a dangerous and hurtful situation is anything but dignifying. As much as we always want to support JT's self-determination in wanting to do things himself without additional supervision, there are times when we have to restrict his self-determination by having an ever-present support person ensure his safety and the safety of others.

JT spends almost every weekend at our family home. He joins us on Saturday for errands and on Sunday for church and family chores. He spends Saturday afternoon at his grandfather's apartment and his grandfather

joins us at our home on Sunday for a day of family meals, conversation, and shared activity.

We take great delight in the reciprocal caregiving JT and his grandfather provide each other. Of the five grandchildren (three in Lawrence, one in D.C., and one in Alabama), JT is the one who calls his grandfather every day and visits with him every week. JT's grandfather, who never took an active role in childcare himself, is always eager to be helpful in any way that he can with JT's support needs.

JT's sisters, Amy and Kate, are now 24 and 21 respectively. Kate has one year left of college and Amy has received her masters degree, will be married this summer, and will start law school in the fall. Because they have attended Kansas University, they have not only been siblings but also friends to JT and an ever-present back-up system for us whenever we needed help and they could possibly arrange to provide it. They learned early on about JT's challenging behavior and what they and others could do to help decrease the likelihood of it occurring. They worry when he goes through the cycles of depression and high levels of anxiety, and their own moods fluctuate according to JT's emotional state.

Additionally, they are aware of the enormous responsibilities that they might need to assume if the two of us die before a person-centered support system can be created for JT that has longevity; and there is the inevitability that some day they will have a greater role than they do now, as we will most likely pre-decease all of our children. We believe very strongly that they deserve the freedom to live their own lives and pursue their own dreams without being restricted by their brother's comprehensive lifestyle needs. On the other hand, we worry that the state-of-art comprehensive lifestyle support that JT now has is totally without the safety net and structure of an agency. If something happened to the two of us as the service coordinators and convenors of JT's Action Group, an enormous hole would be left in his support system, and someone would need to step up to fill it. Kate, JT's younger sister, describes the time that they spend together and her anticipation of the future.

My lunches with JT on Tuesdays are usually the saving grace of my week. If he is in

good spirits, we listen and sing along to James Taylor and John Denver, chit chat over Wendy's frosties and fries, and laugh, a lot. On other days, when he is not in such good spirits, he nervously cleans my car, consistently asks about schedule or other worries on his mind. Some days, he does not even make it to lunch as he does not make it out of bed to go to work. I love my brother, more than anything in the world perhaps. His anxieties sometimes tire me, often frustrate me, and always concern me. See, I just want him to be happy, as we all do. So, when I think about what will happen after my parents die, and my sister and I "take on JT's life," I think about doing whatever it takes to continue those good days at Wendy's when he is courteous, affable, and happy. Lunch with my brother, loving and caring for my brother, has always, and will always be, my first priority. (Kate Turnbull, JT's sister.)

We know Kate's aspirations for theater performance and the strong "call" to experience the theater scene of New York City. We've cherished, nurtured, and delighted in her performance talents since she was a preschooler. How Kate will balance her priorities for career (in which mobility—traveling company—is inherent), artistic expression, a committed relationship with a significant other and her love of her brother, will be part of our family's future journey and adventure. Like comprehensive lifestyle support, the rhetoric of family support is easy; the implementation is incredibly complex with a multitude of potential conflicts of interest.

Pointers for keeping families resilient. All families can be regarded as a "system" (Turnbull & Turnbull, 1997). Whatever affects one member affects the others. That is why it is not surprising that, when JT has challenging behaviors, challenges reverberate through his family—not just in behavioral terms, but in emotional terms as well. The anxiety we feel about his behavior is permanent. True, sometimes it is nearly dormant when all has gone well with him for a couple of weeks but it is activated the minute his behaviors become problematic. For these reasons, a family response—the

family's own "positive behavioral support plan"—is necessary.

- Our family quality of life will be substantially enhanced when JT qualifies for the Medicaid Waiver and receives services characterized by self-determination. This will mean that our Action Group will be able to develop a budget and to receive direct funding to implement the budget in a way that will most maximize JT's quality of life. The day that we can do that cannot come soon enough—we hope within the next several months we will have funding to purchase the services and supports that we have been paying for as a family and also arrange for service coordination from persons other than ourselves.
- We have found that it is critically important for us as a family to have honest and candid communication with each other (and with other members of JT's Action Group) about great expectations, what is working, and what needs to be improved. We also need to discuss our individual and collective capacities at any point in time to invest the time and effort needed to preserve his present supports and to bring about desired but not yet attained changes in his life.
- We need to be able to share our anxieties with each other as honestly as possible; we need mutual affirmation and assistance so we will not be immobilized by ambiguity or worry but rather move optimistically and deliberately toward effective solutions.
- We need to find opportunities to totally get away from responsibilities and then we need to learn to not worry while we are jettisoning our duties. Over the years, we have taken family vacations without JT. That has made us feel guilty at times, but we also knew that we (Ann, Rud, Amy, and Kate) needed to have opportunities to be together and to have those times be free of anticipating JT's mood and anxiety cycles. There have been some vacations when we have found that JT was physically absent but still emotionally present: We simply could not stop worrying about him. As family members, it is critically important to take mental vacations, knowing for a certain

amount of time that whatever happens is not part of our *immediate* responsibility.

- For a long times as a family, we made the basic assumption that “ordinary people” in typical environments would not know how to handle JT’s challenging behavior. We have been surprised and delighted over the years with how many “ordinary people” have demonstrated fantastically good judgment and problem-solving in handling situations that were totally new to them. We’re learning to trust the “safety net of the community” which is, at its most fundamental level, a web of human relationships and the kindness of strangers, “Samaritans.”

Summary and Vision of the Future

We have highlighted JT’s comprehensive lifestyle support in this chapter, but we have in no way covered the full complexities and responsibilities that it involves. We have six degrees between us; sufficient financial resources to purchase the necessary help for JT; and an extensive network of caring family, friends, and professional colleagues who have gone the second, fifth, and even tenth mile in providing support to JT and to us. Nevertheless, it is still extremely demanding to keep all of the “balls juggling” across all of the areas of comprehensive behavior support and to constantly calibrate the support in light of JT’s changing mood and anxiety cycles. If it is a challenge for us, how do single parents with no financial and health care resources, living in “challenged environments”, even begin to support their sons and daughters with similar disabilities and challenging behavior?

Reconfigured Supports

JT needs a high level of support across all of the domains of his life. He has received those supports because his family and friends have constructed them *outside of the present service-delivery system and in spite of the paucity of research* of comprehensive interventions, that will mitigate the effects of his many disabilities. That is why we believe it to be absolutely necessary for us to amend our present ways of being independent of and outside of the service delivery system. Instead, we have to develop, advocate for, or find a different system. What would it

consist of? It would be an agency whose senior and junior staff know us and know and value JT, who are committed to the same visions we have, and who will maintain and improve the supports we have put into place. Our ideal situation would be for an agency to support individuals with disabilities and their families to achieve self-determination by assisting them with service coordination. This service coordination would be targeted on helping them locate competent housemates, job coaches, friends, and community facilitators who would put the supports and services into place that we have described. We would purchase services and supports from the agency with the Medicaid waiver funds.

Such an agency would assist us in staffing the duplex that JT will live in and providing ongoing consultation to his housemates. On one side of the duplex will be JT and his regular (week-day) housemates; on the other, the housemates who will provide support to JT on weekends and for those holidays he does not spend with his family or other loved ones. The two sides of the duplex would connect on the inside (i.e., door created from one side to the other) so the weekend housemates and JT would have easy access to each other while still maintaining the option for privacy. Additionally, the duplex would be on the bus line. It would be close to a shopping center where JT’s necessities can be purchased. It would be big enough (including yard) for him to entertain his guests, up to 50 of them. It would provide privacy for him and his housemates, as well as common rooms. It would provide privacy for him and his housemates, as well as common rooms. It would be in a safe neighborhood, one where JT can move about without being insulted or harmed physically. It would be tasteful, a home with warmth, a welcoming place for all who are part of JT’s life and, most of all, for JT himself. It would be functional, with all the desirable technology and assistive devices that JT needs or can use, a place where repair would be needed only on rare occasions.

If there were one and only one aspect of JT’s and our lives that we could change, that aspect would be understanding the biochemical interaction of his mental retardation, autism, bipolarity, and obsessive-compulsive disorders within his environment. We are convinced that the next major improvements in eliminating his rapid mood and anxiety cycling will have to come

through psycho-pharmacological advances/fine-tuning. The bottom line is that on a 1-10 scale, his environmental support is a 15. We are convinced that we have a tremendous amount yet to learn about JT's biochemical functioning and how that function interacts with his mood and anxiety cycles. We very much wish that there was far more basic and applied research in this critical area of understanding biological and behavioral interactions. We are extremely excited by a new data system we are developing that overlay data on mood, anxiety, OCD behaviors, and work productivity. We believe we are on the frontier of an informative data system that will help us work "upstream" on minimizing his deleterious mood and anxiety cycles (i.e., the root of the problem) rather than "downstream" on his OCD behavioral manifestations (i.e., the outcome of his cycles).

What, then, are the desiderata for JT's enviable life? What, in the ultimate analysis, will make the greatest difference for him, for his family (parents and two sisters for as long as they outlive him), and society? In answering this question, we must bear in mind—and also bear, in the sense of accommodating to the fact—that

- JT is 31 years old;
- it has taken him, us, his friends, the law, and "society" that long to achieve as much as he and we all have achieved so far;
- he will live for another 30 to 40 years; and
- however much research has been done and yet will be done to address the complexities that are inherent in him and however much the laws and societal attitudes will change over the next three to four decades (assuming the changes are favorable to JT—which is always debatable), research is not easily translated into policy, policy does not easily translate into practice, and the certainty of the unknown about JT and the world in which he lives is always the edge upon which progress can be both made or delayed.

Given these considerations, we are deeply disappointed by the data reported by Carr et al. (1999) that only 13% of the outcomes measured in research on positive behavior support over the last 10 years followed someone for six months or more and only 1% of the outcomes tracked people for 13 months or more. Despite the rhetoric that the goal of positive behavior support is to com-

prehensively improve lifestyle outcomes, Carr et al. (1999) reported that lifestyle outcomes were measured for fewer than 3% of the participants.

The bottom line is that there is a huge disparity between the rhetoric about providing comprehensive lifestyle outcomes and research that documents efficacious ways to achieve that goal. We need research to catch up with innovative "family-directed models" such as the support system that JT has and to help illuminate ways to resolve the many difficult issues that come up.

Here is what, at this time and for not much longer than the next decade at the most, will contribute most to JT's comprehensive lifestyle support. We wish that research and model demonstration programs would illuminate the most efficacious support strategies, because we grow weary of "making it up as we go."

Family

First and foremost, JT depends on his family for creating, sustaining, monitoring, and adjusting his lifestyle support. All that is good about his life comes from his family's efforts; and all that is limiting comes from them as well. For the past decade, JT has been supported outside the formal service delivery system. To support his family—his parents and his sisters—is the *sine qua non* of both public policy and comprehensive lifestyle support. It is imaginable what his life would be like without his family's participation over the last ten years; that is not, however, something we want to ponder, for the fact is that JT's life would be impoverished were it not for his family. Likewise, it is imaginable what his life would be like for the next decade without his family; it is not pleasant to conjure. We desperately want to have a system that offers person-centered and family-centered supported living. We do not want JT's support to depend on us nearly as much in the future as it has in the past.

Friends

JT's life is leavened—made to rise like bread—when he has friends. Friendship requires inclusion. Segregation is the enemy of inclusion, of a leavened life. That is why magnificent programs such as the Kansas University's Natural Ties program are so important to him; and that is also why the cultivation of young people into the lives

of such citizens like JT (whether in schools under IDEA's auspices or in a community's rhythms through such activities as the music therapy program at Kansas University) is essential for him (and contributory to the lives of those who enter his life thereby). Any policy that advances inclusion is meritorious; any retreat from inclusion must be fought, tooth and nail. We want support from a system that places high priority on friendship facilitation.

Home of His Own

JT regards himself as a "man" and being a man, if you were to ask him, means living in his own "home" with people who like him and whom he enjoys. That is why family support, tax, anti-discrimination, and other policies have to support home-of-my-own approaches. What JT needs, however, is not just the physical setting and the means to afford it. He also needs housemates who will be with him for 2½ years. JT needs the stability, predictability, understanding, and nurture derived from long-term shared (communal) living. We need for the service system to help JT and us sustain it.

Work

JT is proud that he works. He also benefits from work. First, there is the matter of his salary and such significant fringe benefits as a very good health insurance policy (one that avoids many of the cost and reimbursable expense limitations of Medicaid and that also avoids the stigmatization that comes with being a Medicaid beneficiary). Second, there is the matter of psychic compensation—that sense that comes from contributing. JT needs both. Sheltered employment is not an option: he failed at that, long ago. Supported employment is the only option: he needs the support as much as he needs the work itself. Only one change would enhance his Beach Center work, namely, the extension of his workday by about two hours daily. Also, we think JT would thoroughly enjoy the music production company that Jaimie, his current job coach, earlier described. We can see it in our mind's eye, and we break out in grins. We need assistance from a job developer and job coach to make it happen because we know our own time and energy preclude us from taking such a significant new step through our Action Group alone.

"Cheers Connections"

Having places where everyone knows your name assures JT (and all who are involved in his life) that he is both in and of our community; that he has his own special places to shop, have his hair cut, get his physical checkups, do his banking, enjoy music, and in every other way have access to and meaningful participation in our community. For as long as his family and his housemates are able, we create, and sometimes have to re-create, these Cheers connections. Law cannot, by itself alone, change public attitudes; nor can exemplary practices such as the ones we have launched on JT's behalf. But law that does not facilitate inclusion and research and practice that are based on segregated individuals are simply unacceptable.

Transportation

JT loves to ride the bus and take the taxi; this form of transportation makes him physically independent and emotionally proud. Accessible transportation this becomes a means for lifestyle support: vehicles that he can board and deboard, drivers who come to know him, and dispatchers who will go the extra route to locate him when he rides the wrong bus.

Money

JT is one of those many people with developmental disabilities who are apt to be classified as "WLs"—persons on the "waiting list" for Medicaid services (essentially, home and community-based services). Despite lawsuits in such states as New York and Massachusetts, and despite the advocacy efforts of such organizations as The Arc and the Judge David L. Bazelon Center for Mental Health Law, nearly every state (if not every state) has its "WLs". The promise of Medicaid reform (namely, the home and community-based services "waiver") is great; the reality, however, is not. When JT comes off the waiting list and becomes an active beneficiary, he will receive sufficient funds to purchase nearly all, if not all, of the services and supports he now uses. He will be able to purchase a duplex on the bus-line; and his housemates will have financial support and back-up assistance. This helps us have faith that when we predecease JT or his sisters move away, he will still have an enviable life.

Wrapping It All Up

There are phases of human life. Shakespeare titled them the Seven Ages of Man. JT is now well into the young man age. Within a decade, he will begin his middle age; and within three decades, he will begin his last age. Four ages are gone in his life.

Likewise, there are phases for “the field” (of developmental disabilities and mental health). Nearly thirty years have passed (if we date the beginning in the late 1960s or early 1970s). Laws have been initiated or enacted (IDEA in 1975, Section 504 the same year, ADA in 1990). Many billions of dollars have been invested in research and demonstration programs and in practice based on them but on ideologies as well. And in the last decade alone, millions of research, demonstration, and training dollars have been invested into addressing challenging behaviors of people like JT.

Have those investments been worthwhile? Yes, if the question subsumes the premise that the investments would not have been invested in any way, not at all, in the lives of people with developmental disabilities and mental health challenges. It is better to have had something potentially good than nothing at all or something bad (the perpetuation of the institutional, medical model).

But the question about the worth of the investments can be answered without the categorical, assumption-premised “Yes.” It can be answered, “Yes, but.” Yes, the investments have been important: they have initiated and justified much that has helped people with disabilities such as JT’s. But they have not helped enough.

We have the sense that the rights revolution that began in the late 1960s and early 1970s is, like JT, in the young-man age. BUT we also have the sense that “the field”—the rights-advocates, the researchers, the practitioners, and the families—are not prepared for, and are not even beginning to prepare, for the middle age, for the next phase.

Of course, some of the leadership in “the field” is anticipating and setting the future. Ironically, they seem to be saying that what they and their colleagues created to address the problems of the last 25 years was suitable for then but is not suitable for tomorrow. We ourselves believe that to be the case.

Making marginal improvements on what we already know and tweaking systems that were devised to fit the horrific problems of the early 1970s—these two approaches seem to us to be simply solidifying a system, an approach, that is too ripe with shortcomings already. We fail to see the sense of improving a system that is already outmoded.

What makes us think that the system is outmoded—that system of research, demonstration, service-delivery, and training? It is, as we have tried to make clear, that it does not work well enough for JT and his family, friends, and community; and it most likely does not work well enough for others either.

We ourselves seek to “recapture the revolution”—to experience again the sense of adventure in the pursuit of a different way to be, of a different way to live joyfully and productively. But we are cautious, indeed, we are skeptical, that we should try to sustain the prevalent models created from a 1970 rather 2000 mentality.

Something is amiss in JT’s life, in the lives of people like him, in the lives of families like ours. We search for it, we set out here some pointers that may guide us all toward it. But the comprehensive vision—the Camelot that we see when we shut our eyes and free ourselves of the fetters of today—has yet to be captured. It is time—yes, it is past time—to recapture the revolution. But it has to be a different revolution—one focused on JT and other individuals with disabilities “getting a life” at the same “standard” and “rhythm” of living as enjoyed by citizens without disabilities. And the revolution has to place equal value on professional knowledge from research and experiential knowledge from families and self-advocates. The revolutionary agenda will not succeed if professionals dominate it. We are calling for authentic and equal partnerships. Comprehensive lifestyle support—we are overdue in moving from rhetoric to reality for the benefit of individuals with challenging behavior and their families.

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